

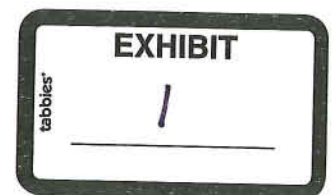


# **Interdepartmental Serious Mental Illness Coordinating Committee**

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The Way Forward: Federal Action for a System That  
Works for All People Living With SMI and SED and Their  
Families and Caregivers

December 13, 2017




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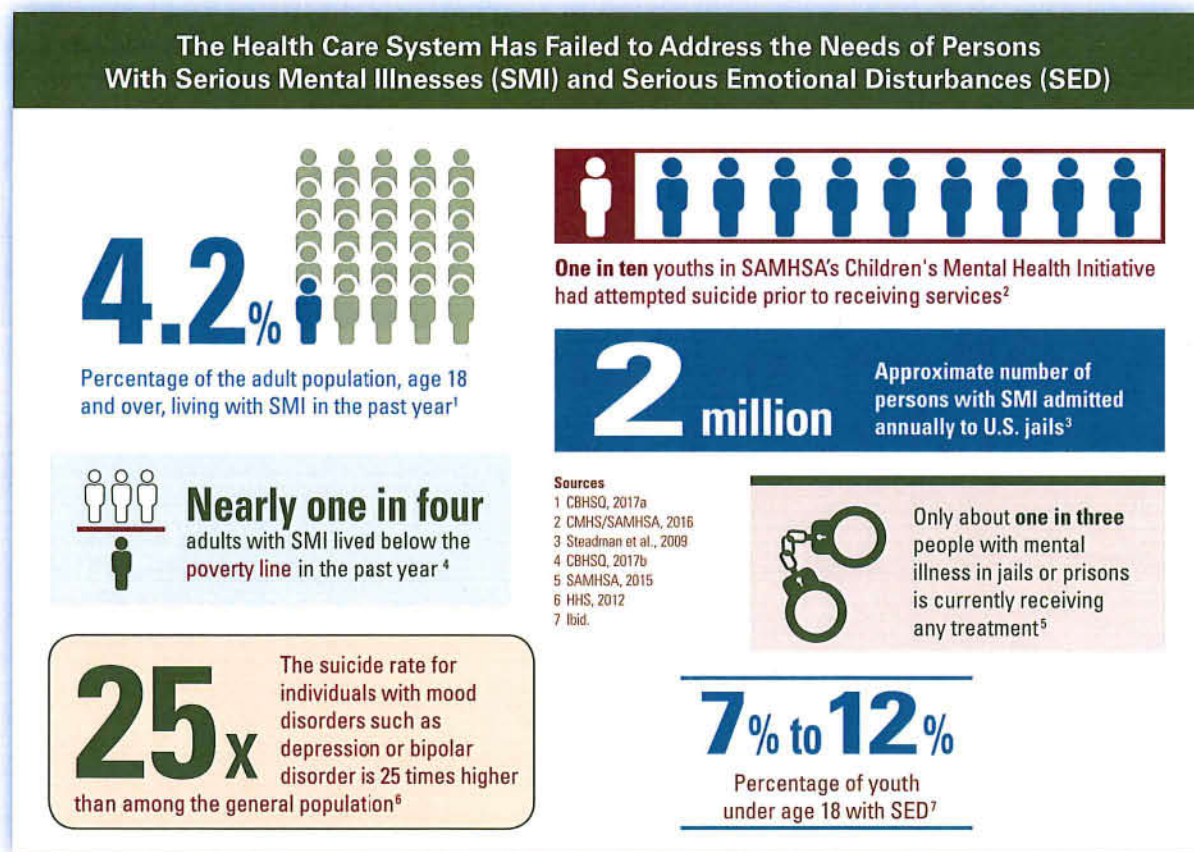




## Introduction

In 2003, the President's New Freedom Commission on Mental Health concluded that America's mental health service delivery system was in shambles. The Commission's final report stated that "for too many Americans with mental illnesses, the mental health services and supports they need remain fragmented, disconnected and often inadequate, frustrating the opportunity for recovery." A number of the recommendations of the President's New Freedom Commission on Mental Health were not implemented or have only been partially realized. Since then, quality of life has not fundamentally changed for adults with serious mental illnesses (SMI) and children and youth with serious emotional disturbances (SED) and their families in the United States (Figure 1).

**Figure 1. Estimates and Unmet Needs of Persons With Serious Mental Illnesses and Serious Emotional Disturbances**





Poor social supports, unemployment, comorbid medical problems, and addiction challenges abound. We have continued to defer to law enforcement services, criminal justice systems, hospital services, public education systems, and homeless services as the primary solutions, overtaxing these services and systems while contributing to poor outcomes such as unnecessary incarceration and long waits in hospital emergency departments. Failure to succeed in school or to access higher education, housing, or employment remain all too common. Tragically, people with SMI and SED die of suicide at extremely high rates, and in rare circumstances violence has led to unspeakable pain for families and our communities.

"My adult son has cycled 13 times through mental hospitals over a 3-year period. He is taking his medications but continues to have psychotic thoughts not based in reality, and is greatly disabled by them. What has transpired since the closing of psychiatric care facilities is a travesty: incarceration, multiple cycles through hospitals or ERs, and homelessness, and often deaths. Without access to adequate care, many family members are caught in impossible situations, become distraught, or give up entirely. We need a federal standard and community solutions to provide care for highly disabled, mentally ill people like my son."

— Marilyn (submitted through public comments to the ISMICC)

Negative attitudes and discrimination remain a painful part of every setting, including school, work, and health care, preventing children, youth, and adults with serious mental health conditions from being embraced and valued in their communities. When individuals and their families don't seek help because of negative attitudes and discrimination, they don't access services and supports that could improve their situations, and this prevents them from exercising their legal rights under the Americans with Disabilities Act and the Individuals with Disabilities Education Act.

## Role of the ISMICC

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The 21st Century Cures Act (Public Law 114-255) authorizes the Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC) to enhance coordination across federal agencies to improve service access and delivery of care for people with SMI and SED and their families. The ISMICC is charged to:

- Report on advances in research on SMI and SED related to prevention, diagnosis, intervention, treatment and recovery, and access to services and supports;
- Evaluate the effect federal programs related to SMI and SED have on public health, including outcomes across a number of important dimensions; and
- Make specific recommendations for actions that federal departments can take to better coordinate the administration of mental health services for adults with SMI or children with SED.

The ISMICC is chaired by Dr. Elinore F. McCance-Katz, Assistant Secretary for Mental Health and Substance Use. This position brings a new level of authority, experience, and expertise to the coordination of efforts at the Department of Health and Human Services (HHS) to address the needs of people with SMI and SED. Dr. McCance-Katz and other federal members on the Committee will work across HHS and the federal government so Americans with SMI and SED are able to improve their lives and have access to the highest possible standard of care—care that is deeply informed by our knowledge of science and medicine.

The ISMICC is a historic chance to address SMI and SED across federal departments and the systems that they represent. Each of the eight departments supports programs that address the needs of people with SMI and SED. Their collaboration will be informed and strengthened by the participation of non-federal members, including national experts on health care research, mental health providers, advocates, and people with mental health conditions and their families and caregivers. The ISMICC is currently authorized through 2022, at which time the Secretary of HHS will submit a recommendation to Congress about whether to extend the ISMICC.

**Federal Department and Agency Representation  
on the ISMICC**

- Secretary of the Department of Health and Human Services
- Assistant Secretary for Mental Health and Substance Use
- Attorney General, Department of Justice
- Secretary of the Department of Veterans Affairs
- Secretary of the Department of Defense
- Secretary of the Department of Housing and Urban Development
- Secretary of the Department of Education
- Secretary of the Department of Labor
- Administrator of the Centers for Medicare & Medicaid Services
- Commissioner of the Social Security Administration

The non-federal ISMICC members have firsthand experience with the mental health service system, and knowledge of what barriers exist for people who are seeking help. Moreover, the non-federal members bring on-the-ground solutions and innovative ideas that can promote change and improve lives, in partnership with the federal members.

Together, ISMICC members bring the experience needed to develop a better understanding of what is working and what needs to be changed within the current systems of care. (See Appendix A for the full ISMICC membership.) This cross-sector, public-private partnership provides a unique opportunity to share and generate solutions not previously considered or implemented.

By strengthening federal interdepartmental leadership and coordination, we can change federal policy to improve the availability and quality of care for people served. Improvement will come not just through the provision of more health care services, but through a more holistic approach—a true continuum of care that makes sense for each unique person. We seek to build a system where treatment and services work and individuals with SMI and SED can recover and live happier, healthier, more productive, and more connected lives.



## The 2017 ISMICC Report to Congress

The work of the ISMICC is just beginning. This 2017 ISMICC Report to Congress includes information presented in the first ISMICC meeting in August 2017 and from ongoing dialogue with the ISMICC members. This report will set the stage for work by the ISMICC in the years ahead.

The ISMICC identified five major areas of focus for fulfilling the Committee's vision. The five areas will guide the Committee's work. We know that important treatment advances are on the horizon. Research is identifying new and powerful ways to improve the ability to diagnose and identify risk factors for the course of mental illnesses. Sensitive to emerging science, the ISMICC members plan to revisit this report, its charge, and the areas of focus periodically in the coming years.

The final ISMICC report to Congress is due December 2022 and will provide more complete information on what the ISMICC has accomplished and will identify future opportunities for improving the lives of those with SMI and SED. The ISMICC will develop interim reports and other documents as needed to further the progress of the Committee's work.

### Five ISMICC Areas of Focus

1. Strengthen federal coordination to improve care
2. Access and engagement: Make it easier to get good care
3. Treatment and recovery: Close the gap between what works and what is offered
4. Increase opportunities for diversion and improve care for people with SMI and SED involved in the criminal and juvenile justice systems
5. Develop finance strategies to increase availability and affordability of care

The ISMICC will serve as a model for cross-sector coordination and will promote partnerships to address the needs of people with SMI and SED and their families and caregivers. We anticipate that the work of the ISMICC will stimulate change across federal and non-federal sectors. Federal efforts will help build new relationships and partnerships across public sectors, agencies, and levels of government. A commitment to coordinate and collaborate at the federal, state, tribal, county, and local levels will lead to systems that are easy to navigate, appropriate, and tailored to the individual needs of each person and their family and caregivers.



## **ISMICC Vision Statement**

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Federal interdepartmental leadership, with genuine collaboration and shared accountability of all federal agencies, and in partnership with all levels of government and other stakeholders, supports a mental health system that successfully addresses the needs of all individuals living with SMI or SED and their families and caregivers, effectively supporting their progress to achieve healthy lives characterized by autonomy, pride, self-worth, hope, dignity, and meaning.

## **Recommendations From the Non-Federal Members Summary<sup>1</sup>** **(See Chapter 4 for Full Recommendations)**

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### **Focus 1: Strengthen Federal Coordination to Improve Care**

- 1.1. Improve ongoing interdepartmental coordination under the guidance of the Assistant Secretary for Mental Health and Substance Use.
- 1.2. Develop and implement an interdepartmental strategic plan to improve the lives of people with SMI and SED and their families.
- 1.3. Create a comprehensive inventory of federal activities that affect the provision of services for people with SMI and SED.
- 1.4. Harmonize and improve policies to support federal coordination.
- 1.5. Evaluate the federal approach to serving people with SMI and SED.
- 1.6. Use data to improve quality of care and outcomes.
- 1.7. Ensure that quality measurement efforts include mental health.
- 1.8. Improve national linkage of data to improve services.


### **Focus 2: Access and Engagement: Make It Easier to Get Good Care**

- 2.1. Define and implement a national standard for crisis care.

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<sup>1</sup> These recommendations reflect the views of the non-federal ISMICC members. Federal members were consulted regarding factual concerns and federal processes, but the final list of recommendations are the product of the non-federal members. These recommendations do not represent federal policy, and the federal departments represented on the ISMICC have not reviewed the recommendations to determine what role they could play in the future activities of the departments. The recommendations should not be interpreted as recommendations from the federal government.



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- 2.2. Develop a continuum of care that includes adequate psychiatric bed capacity and community-based alternatives to hospitalization.
  - 2.3. Educate providers, service agencies, people with SMI and SED and their families, and caregivers about the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and other privacy laws, including 42 CFR Part 2, in the context of psychiatric care.
  - 2.4. Reassess civil commitment standards and processes.
  - 2.5. Establish standardized assessments for level of care and monitoring of consumer progress.
  - 2.6. Prioritize early identification and intervention for children, youth, and young adults.
  - 2.7. Use telehealth and other technologies to increase access to care.
  - 2.8. Maximize the capacity of the behavioral health workforce.
  - 2.9. Support family members and caregivers.
  - 2.10. Expect SMI and SED screening to occur in all primary care settings.

### **Focus 3: Treatment and Recovery: Close the Gap Between What Works and What Is Offered**

- 3.1. Provide a comprehensive continuum of care for people with SMI and SED.
- 3.2. Make screening and early intervention among children, youth, transition-age youth, and young adults a national expectation.
- 3.3. Make coordinated specialty care for first-episode psychosis available nationwide.
- 3.4. Make trauma-informed, whole-person health care the expectation in all our systems of care for people with SMI and SED.
- 3.5. Implement effective systems of care for children, youth, and transition-age youth throughout the nation.
- 3.6. Make housing more readily available for people with SMI and SED.
- 3.7. Advance the national adoption of effective suicide prevention strategies.
- 3.8. Develop a priority research agenda for SED/SMI prevention, diagnosis, treatment, and recovery services.


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- 3.9. Make integrated services readily available to people with co-occurring mental illnesses and substance use disorders, including medication-assisted treatment (MAT) for opioid use disorders.
  - 3.10. Develop national and state capacity to disseminate and support implementation of the national standards for a comprehensive continuum of effective care for people with SMI and SED.

**Focus 4: Increase Opportunities for Diversion and Improve Care for People With SMI and SED Involved in the Criminal and Juvenile Justice Systems**

- 4.1. Support interventions to correspond to all stages of justice involvement. Consider all points included in the sequential intercept model.
- 4.2. Develop an integrated crisis response system to divert people with SMI and SED from the justice system.
- 4.3. Prepare and train all first responders on how to work with people with SMI and SED.
- 4.4. Establish and incentivize best practices for competency restoration that use community-based evaluation and services.
- 4.5. Develop and sustain therapeutic justice dockets in federal, state, and local courts for any person with SMI or SED who becomes involved in the justice system.
- 4.6. Require universal screening for mental illnesses, substance use disorders, and other behavioral health needs of every person booked into jail.
- 4.7. Strictly limit or eliminate the use of solitary confinement, seclusion, restraint, or other forms of restrictive housing for people with SMI and SED.
- 4.8. Reduce barriers that impede immediate access to treatment and recovery services upon release from correctional facilities.
- 4.9. Build on efforts under the Mentally Ill Offender Treatment and Crime Reduction Act, the 21<sup>st</sup> Century Cures Act, and other federal programs to reduce incarceration of people with mental illness and co-occurring substance use disorders.

**Focus 5: Develop Finance Strategies to Increase Availability and Affordability of Care**

- 5.1. Implement population health payment models in federal health benefit programs.
- 5.2. Adequately fund the full range of services needed by people with SMI and SED.

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- 5.3. Fully enforce parity to ensure that people with SMI and SED receive the mental health and substance abuse services they are entitled to, and that benefits are offered on terms comparable to those for physical illnesses.
  - 5.4. Eliminate financing practices and policies that discriminate against behavioral health care.
  - 5.5. Pay for psychiatric and other behavioral health services at rates equivalent to other health care services.
  - 5.6. Provide reimbursement for outreach and engagement services related to mental health care.
  - 5.7. Fund adequate home- and community-based services for children and youth with SED and adults with SMI.
  - 5.8. Expand the Certified Community Behavioral Health Clinic (CCBHC) program nationwide.





## References

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- Center for Behavioral Health Statistics and Quality (CBHSQ). (2017a). *2016 National Survey on Drug Use and Health: Detailed Tables*. (NSDUH 2016, Table 8.6B). Rockville, MD: Substance Abuse and Mental Health Services Administration.
- Center for Behavioral Health Statistics and Quality (CBHSQ). (2017b). *2016 National Survey on Drug Use and Health: Detailed Tables*. (NSDUH 2016, Table 8.6A). Rockville, MD: Substance Abuse and Mental Health Services Administration.
- Center for Mental Health Services (CMHS), Substance Abuse and Mental Health Services Administration (SAMHSA). (2016). *The evaluation of the comprehensive community mental health services for children with serious emotional disturbances program, report to Congress, 2015* (SAMHSA Publication No. PEP16-CMHI2015). Retrieved from [https://www.samhsa.gov/sites/default/files/programs\\_campaigns/nitt-ta/2015-report-to-congress.pdf](https://www.samhsa.gov/sites/default/files/programs_campaigns/nitt-ta/2015-report-to-congress.pdf).
- President's New Freedom Commission on Mental Health. (2003). *Achieving the Promise: Transforming Mental Health Care in America*. Retrieved from <http://govinfo.library.unt.edu/mentalhealthcommission/reports/FinalReport/downloads/FinalReport.pdf>.
- Steadman, H. J., Osher, F. C., Robbins, P. C., Case, B., & Samuels, S. (2009). Prevalence of serious mental illness among jail inmates. *Psychiatric Services*, 60(6), 761-765.
- Substance Abuse and Mental Health Services Administration (SAMHSA). (2015). *Screening and assessment of co-occurring disorders in the justice system*. (HHS Publication No. (SMA)-15-4930). Rockville, MD: Substance Abuse and Mental Health Services Administration.
- U.S. Department of Health and Human Services (HHS) Office of the Surgeon General and National Action Alliance for Suicide Prevention. (2012). *2012 national strategy for suicide prevention: Goals and objectives for action*. Washington, DC: U.S. Department of Health & Human Services. Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK109917>.







# Chapter 1: The Current Needs of Americans With Serious Mental Illnesses and Serious Emotional Disturbances

This report focuses on issues related to adults with serious mental illnesses (SMI) and children and youth with serious emotional disturbances (SED).

## Serious Mental Illnesses

The definition of SMI includes one or more diagnoses of mental disorders combined with significant impairment in functioning. Schizophrenia, bipolar illness, and major depressive disorder are the diagnoses most commonly associated with SMI, but people with one or more other disorders may also fit the definition of SMI if those disorders result in functional impairment.

### Defining SMI<sup>2</sup>

Serious mental illness (SMI) refers to individuals 18 or older, who currently or at any time during the past year have had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified in the diagnostic manual of the American Psychiatric Association and that has resulted in functional impairment, that substantially interferes with or limits one or more major life activities.

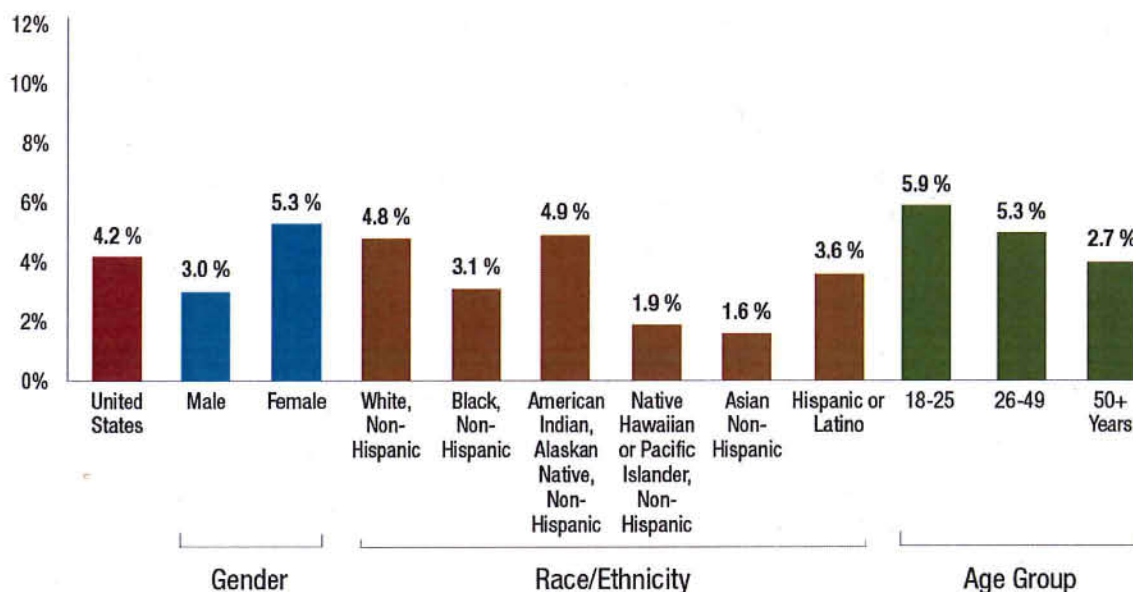
Major life activities include basic daily living skills (e.g., eating, bathing, dressing); instrumental living skills (e.g., maintaining a household, managing money, getting around the community, taking prescribed medication); and functioning in social, family, and vocational/educational contexts.

**About 1 in 25 adults has an SMI in a given year.** In 2016, 4.2 percent of U.S. adults age 18 or older (an estimated 10.4 million adults) had an SMI in the past year (CBHSQ, 2017a). This estimate includes new and existing cases of SMI. The percentage of SMI in the past year was higher for sexual minority adults (13.1 percent) than for sexual majority adults (3.6 percent) (Medley et al., 2016). Across racial and ethnic groups, people of two or more races (7.5 percent) and Non-Hispanic Whites (4.8 percent) had higher percentages of SMI in the past year than the national average (4.2 percent) (Figure 1.1). In 2016, women accounted for 65.4 percent of adults with SMI (CBHSQ, 2017a).

The percentage of SMI in the past year also varies across age groups, with those 50 and older (2.7 percent) having lower rates than those aged 18 to 25 (5.9 percent) or those aged 26 to 49 (5.3 percent). The lower prevalence in older adults may be impacted by the increased risk of earlier death among people with SMI.

<sup>2</sup> For the precise wording of the definition, see <https://www.samhsa.gov/sites/default/files/federal-register-notice-58-96-definitions.pdf>. Note that impairment resulting from a primary diagnosis of substance use disorder does not qualify a person as having a serious mental illness. This report does not address Alzheimer's disease or related disorders that are listed in the Diagnostic and Statistical Manual of Mental Disorders and cause functional impairment. The ISMICC has noted the need for consistent definitions of SMI and SED and is considering how best to address these definitional issues moving forward.

**Figure 1.1. Past Year Serious Mental Illness (SMI) Among Adults Age 18 or Older in the United States, by Gender, Race/Ethnicity, Age Group: 2016**



**Source:** Center for Behavioral Health Statistics and Quality. (2017). *Results from the 2016 National Survey on Drug Use and Health: detailed tables*. Rockville, MD: Substance Abuse and Mental Health Services Administration.

**Adults with SMI often have multiple chronic conditions and general health issues.** As stated by the Institute of Medicine<sup>3</sup> (Daniels, England, Page, and Corrigan, 2005), “Mental and substance-use problems and illnesses seldom occur in isolation. They frequently accompany each other, as well as a substantial number of general medical illnesses such as heart disease, cancers, diabetes, and neurological illnesses. ... Because of this, mental, substance-use, and general health problems and illnesses are frequently intertwined, and coordination of all these types of health care is essential to improved health outcomes, especially for chronic illnesses.” People with co-occurring disorders often experience difficulty seeking and receiving services, which leads to poorer health outcomes overall and utilization of high-cost services such as inpatient and emergency room care. These individuals need to receive integrated care in settings equipped to diagnose and treat these complex and interrelated disorders (SAMHSA, 2002).

Nearly three-quarters of adults with SMI are diagnosed with two or more mental disorders (Kessler, Chiu, Demler, & Walters, 2005). About a quarter of adults with SMI (25.4 percent, an

<sup>3</sup> Now known as the National Academy of Medicine



estimated 2.6 million adults) have a substance use disorder (Figure 1.2) (CBHSQ, 2017b), and approximately one in six (16.1 percent) misused opioids in the past year (CBHSQ, 2017c). Adults with SMI and substance use disorders “show more severe symptoms of mental illness, more frequent hospitalizations, more frequent relapses, and a poorer course of illness than patients with a single diagnosis, as well as higher rates of violence, suicide, and homelessness” (Bellack, Bennett, Gearon, Brown, & Yang, 2006). Nearly half of people with SMI used tobacco in the past year (49 percent) (CBHSQ, 2017d). A growing body of research shows that quitting smoking can improve mental health and addiction recovery outcomes (SAMHSA, n.d.-a); for example, smoking cessation is associated with a decreased risk of anxiety and mood disorders (Cavazos-Rehg et al., 2014).

**Figure 1.2. Past Year Substance Use Disorder (SUD) and Serious Mental Illness (SMI) Among Adults Age 18 or Older: 2016**

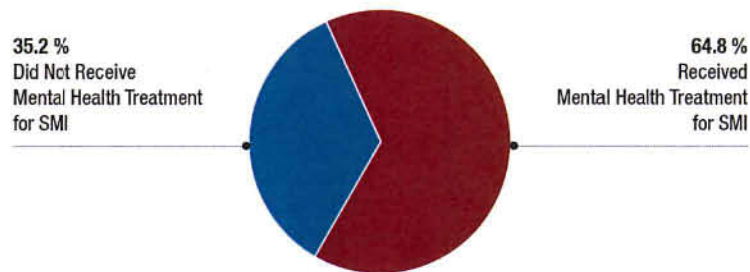


**Source:** Adapted from Figure 69 of: Substance Abuse and Mental Health Services Administration. (2017). *Key substance use and mental health indicators in the United States: Results from the 2016 National Survey on Drug Use and Health* (HHS Publication No. SMA17-5044, NSDUH Series H-52). Retrieved from <http://www.samhsa.gov/data>.

**Relatively few adults with SMI receive effective treatments.** Treatments that are demonstrated to be effective for SMI may include some combination of prescription medications, other supports (e.g., inpatient treatment, respite care, assertive community treatment, coordinated specialty care, supported employment), and psychotherapy (e.g., cognitive behavioral therapy, cognitive remediation therapy). About two-thirds of adults with SMI (64.8 percent, an estimated 6.7 million adults) (CBHSQ, 2017e) reported receiving mental health treatment in 2016 (Figure 1.3). Most treatment is offered in outpatient settings, with only 7.6 percent (an estimated 789,000 adults) receiving inpatient mental health treatment/counseling in the past year (CBHSQ, 2017f). Nearly a third (32.6 percent, 2.2 million adults) of those who get treatment receive medications only, with no psychosocial or psychotherapeutic services (CBHSQ, 2017g). Among adults with co-occurring SMI and substance use disorders, nearly two-thirds (63.2 percent) received mental health care, but only 14.3 percent received specialized substance use treatment (Figure 1.4).

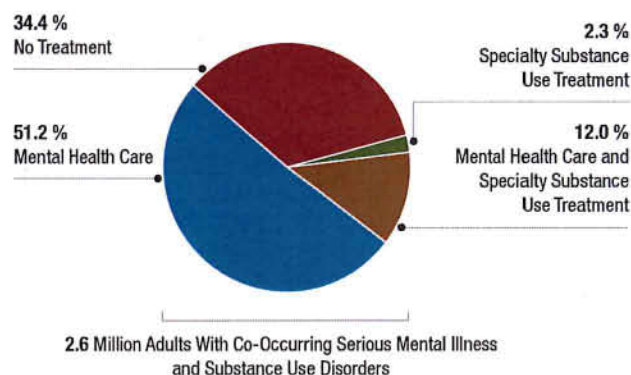


**Figure 1.3. Receipt of Mental Health Services in the Past Year Among Adults Age 18 or Older With Serious Mental Illness (SMI): Percentages, 2016**



**Source:** Adapted from Table 8.33 of: Center for Behavioral Health Statistics and Quality. (2017). *2016 national survey on drug use and health: Detailed tables*. Rockville, MD: Substance Abuse and Mental Health Services Administration.

**Figure 1.4. Receipt of Mental Health Care and Specialty Substance Use Treatment in the Past Year Among Adults Age 18 or Older Who Had Past Year Serious Mental Illness and Substance Use Disorders: Percentages, 2016**



**Source:** Adapted from Figure 73 of: Substance Abuse and Mental Health Services Administration. (2017). *Key substance use and mental health indicators in the United States: Results from the 2016 National Survey on Drug Use and Health* (HHS Publication No. SMA17-5044, NSDUH Series H-52). Retrieved from <http://www.samhsa.gov/data>.

**Effective treatment models exist, but are not widely available.** States report annually on the implementation of select evidence-based practices (EBPs) in their systems. EBPs are practices that are based on rigorous research that has demonstrated effectiveness in achieving the outcomes that the practices were designed to achieve. State mental health systems often serve those with mental health conditions, including SMI and SED, who are Medicaid eligible and whose conditions require levels of care not paid for by private insurance. The percentage of the population who have access to these EBPs remains low and varies widely across states, recognizing that not all EBPs are appropriate for all people with SMI or SED (Table 1.1). For example, assertive community treatment, an intensive team-based care model that is a long-established best practice for adults with SMI, is provided to only 2.1 percent of the people served in state systems nationwide. Similarly, the individual placement and support model of supported employment, which should be provided to all adults with SMI who have a goal of employment, also is provided to only 2.1 percent of adults in state systems.


**Table 1.1. Populations Receiving Select Evidence-Based Practices in Selected State Mental Health Systems in 2016<sup>4</sup>**

Evidence-Based Practice	Target Population for Service	Percent of State MH Population Who Receive Practice in States that Report Data
Medication management	Adults and youth with SMI/SED	32.0%
Illness self-management	Adults with SMI	19.0%
Dual diagnosis treatment	Adults with SMI and SUD	10.5%
Assertive community treatment	Adults with SMI	2.1%
Supported employment	Adults and transition-age youth with SMI	2.1%
Supported housing	Adults and transition-age youth with SMI	3.1%
Therapeutic foster care	Children and youth with SED	1.5%
Multi-systemic therapy	Children and youth with SED	3.6%
Functional family therapy	Children and youth with SED	6.9%
Family psychoeducation	Families of people with SMI	1.9%

**Most counties in the United States face shortages of mental health professionals.** In 96 percent of the counties in the nation, there is a shortage of psychiatrists who prescribe medications for people with SMI (Thomas, Ellis, Konrad, Holzer, & Morrissey, 2009). From 2003 to 2013, the number of practicing psychiatrists decreased by 10 percent when adjusted for population size (Bishop, Seirup, Pincus, & Ross, 2016). Many psychiatrists are shifting to private practice, accepting only cash for reimbursement. In part, this may reflect low reimbursement

<sup>4</sup> From SAMHSA Uniform Reporting System Data - <https://www.dasis.samhsa.gov/dasis2/urs.htm>. These figures only represent a subset of states that provided data.





for psychiatric services from state Medicaid programs and Medicaid-contracted managed care payers, cuts to federal and state funding for public sector programs, and inadequate rate setting for psychiatric services (Bishop, Press, Keyhani, & Pincus, 2014; National Council Medical Director Institute, 2017). The greatest shortages are in poorer and more rural counties. The need for child psychiatrists is even greater than the shortage of psychiatrists for adults with SMI (Thomas & Holzer, 2006). The lack of access to psychiatric services creates several issues, such as long wait times for scheduled appointments, often leading to emergency department visits and hospitalizations (National Council Medical Director Institute, 2017).

Expanding the workforce by allowing advanced practice registered nurses to practice to the full extent of their training, broadening the scope of practice of psychologists to prescribe some medications, and educating more advanced practice registered nurses and psychiatric-mental health physician assistants, are examples of strategies to address the shortage. Tele-mental health is widely accepted as a mechanism that can address shortages in some geographic areas. One county in five also has a shortage of non-prescriber mental health professionals, defined as psychologists, advanced practice psychiatric nurses, social workers, licensed professional counselors, and marriage and family therapists (Thomas, Ellis, Konrad, Holzer, & Morrissey, 2009). Also, there are categories of mental health service providers, including licensed professional counselors and marriage and family therapists, whose services are not eligible for reimbursement by Medicare (CMS, 2015). Peer support can play an important role in a functioning mental health system and should be included as a part of a full continuum of services, whenever possible (Myrick & del Vecchio, 2016). Peer support services have been demonstrated to promote recovery and resiliency through the generation of hope, engagement in treatment services, and activation for improved health outcomes (Repper & Carter, 2011). Youth and family peer support services have also generated notable outcomes in this area (Center for Health Care Strategies, 2013).

**Most states report insufficient psychiatric crisis response capacity as well as insufficient numbers of inpatient psychiatric hospital beds.** It is critical that every state have adequate bed capacity to respond to the needs of people experiencing both psychiatric crises and those who are in need of longer periods of inpatient care, such as people in forensic care (care that is provided because of involvement in the criminal or juvenile justice systems). In many areas, bed shortages have led to long delays in gaining access to treatment and an increase in individuals waiting for competency restoration services needed to restore competency to participate in legal proceedings (NASMHPD, 2017a). A report by the National Association of State Mental Health Program Directors Research Institute (NASMHPD, 2017b) found that most states (35 of the 46 who responded) have shortages of psychiatric hospital beds. The configuration of available beds and the number of beds per 100,000 population varies substantially across states, but few states report they have adequate numbers of inpatient beds to meet needs. Use of a variety of strategies, such as building psychiatric respite bed capacity, may help to address these capacity issues.



**Adults with SMI are more likely to be jailed or involved with the criminal justice system.**

It is estimated that approximately two million people with SMI are admitted annually to U.S. jails (Steadman, Osher, Robbins, Case, & Samuels, 2009). Among these admissions, 72 percent also meet criteria for co-occurring substance use disorders (Hyde, 2011). In 2016, among U.S. adults age 18 or older with SMI, 9.5 percent were on probation and 9.7 percent were on parole or supervised release (CBHSQ, 2017h). By comparison, 2.9 percent of the general U.S. adult population is currently under some form of criminal justice supervision (SAMHSA, 2015). Too few jails and prisons offer screening and treatment programs for mental and substance use disorders, leading to longer incarceration stays (SAMHSA, 2015). All states require efforts to restore legal competence after a person is determined to be incompetent to stand trial, a process that typically takes place in state hospitals. However, a lack of available hospital beds for competency restoration can lead to waits for pretrial jail detainees that may average weeks, or even a year or longer (Fuller, Sinclair, Lamb, Cayce, & Snook, 2017). Only about one in three people with mental illness in jails or prisons receives any treatment (Bronson & Berzofsky, 2017). These factors contribute, in turn, to higher rates of recidivism. Specialty courts for people with mental or substance use disorders are promising, but their availability is extremely limited.

"Successful reentry into the community is a challenge for returning inmates with SMI. They are more likely than returning inmates without SMI to experience homelessness and are less likely to find employment."

— Conclusions from a systematic review by the  
Agency for Healthcare Research and Quality  
(AHRQ, 2012)

**Many adults with SMI are unemployed.** Only 36 percent (CBHSQ, 2017a) of people with SMI have full-time employment, while most would prefer to work (McQuilken, Zahniser, Novak, Starks, Olmos & Bond, 2003). SMI also is a major driver of disability: 24.55 percent of adult disability applications in Federal Fiscal Year 2016 to the Social Security Administration were based on mental health, as were 64.56 percent of childhood disability applications (Social Security Administration, 2017).

**Nearly twice as many adults with SMI have incomes below the poverty level as in the general population (22.8 percent, compared to 13.5 percent)** (CBHSQ, 2017i; U.S. Census Bureau, n.d.).

**SMI is common among people experiencing homelessness.** The Department of Housing and Urban Development (HUD) and SAMHSA (SAMHSA, n.d.-b) estimate that about one in five people (nearly 108,000 people) (HUD, 2016) experiencing homelessness has an SMI, and a similar percentage have a chronic substance use disorder. The Office of National Drug Control Policy reports that approximately 30 percent of people who are chronically homeless live with an SMI (Office of National Drug Control Policy, n.d.).

**Most adults with SMI have private insurance or Medicaid.** About one-quarter (24.9 percent) of adults with SMI were enrolled in Medicaid at some time during 2015, while slightly more than



half (51.5 percent) had private insurance during the year. For some period of the year, more than 1 in 10 (12.5 percent) had no insurance (CBHSQ, 2017i). However, individuals with insurance may still face challenges in accessing treatment. For example, many individuals with SMI still lack a usual source of care or delay medical care because of cost (Sherrill & Gonzales, 2017). An analysis of the 2016 Affordable Care Act Marketplaces demonstrated that, of those practicing in a given state-level market, plan networks included mental health care providers at a much lower rate (11.3 percent) in comparison to primary care providers (24.3 percent) (Zhu, Zhang, & Polsky, 2017).

**Adults with SMI are at particularly high risk of death by suicide.** A suicide occurs in the United States about every 13 minutes (Centers for Disease Control and Prevention [CDC], 2015); more than 44,000 suicides occurred in 2015 (CDC, 2017). According to the Surgeon General's National Strategy for Suicide Prevention (HHS, 2012), the rate of death by suicide for people with mood disorders such as depression or bipolar disorder is estimated to be 25 times higher than among the general population.

Among adults diagnosed with schizophrenia, 1 in 20 dies by suicide, a rate 20 times higher than for the general populations (Hor & Taylor, 2010).

"My 39-year old son killed himself today. He hung himself in a solitary confinement cell in a prison. He died alone, afraid, and powerless. He needed help. Instead, he got punishment. Like all mothers, I had dreams for my children – dreams that didn't include mental illness or prison."

—Anne (submitted through public comments to the ISMICC)

**Mental illnesses lead to high medical costs.** Health care costs are increased by two to three times for people with mental illness, even if their conditions are not among the most serious (Melek, Norris & Paulus, 2014). It is noteworthy that most of these higher costs for people with mental disorders result from medical spending for chronic health conditions, not for behavioral health medications or services. A high proportion of the most costly patients served by the health care system have mental or substance use disorders (Boyd et al., 2010). High medical costs are often incurred at hospitals, due to emergency department visits and hospitalizations. Between 2006 and 2014, the rate of mental health/substance abuse-related emergency department visits increased approximately 44 percent (Moore, Stocks, & Owens, 2017). In 2014, people diagnosed with schizophrenia or mood disorders made 10.8 million visits to emergency departments (HCUP, 2014a). Hospitalizations for people with schizophrenia or mood disorders cost \$27.7 billion nationwide (HCUP, 2014b).

**Adults with mental illness receive a disproportionate share of opioid prescriptions.** While people with any mental health condition represent only 17.9 percent of the population, a recent study concluded: "Adults with mental health conditions receive 51.4 percent (60 million of 115 million prescriptions) of the total opioid prescriptions distributed in the United States each year" (Davis, Lin, Liu, & Sites, 2017).

**Most civil commitment statutes fall short of adequately protecting patients or communities.** In many jurisdictions, civil commitment criteria focus primarily on the immediate



threat of harm to self or others and do not consider patient history or capacity to make informed decisions about the need for or benefits of treatment (Goldman, 2014). This results in many patients being unable to access care when decompensated until they have done something which may lead to their arrest. Although virtually all states have legal provisions for the use of assisted outpatient treatment (AOT), this form of court-ordered outpatient treatment is realistically available in few areas in the nation currently. AOT can be valuable to help ensure that people with SMI who are at high risk of damaging behavior are engaged at some level with treatment services. SAMHSA currently is working with the HHS Assistant Secretary for Planning and Evaluation and the National Institute of Mental Health to evaluate the effect of various aspects of AOT implementation in 17 communities throughout the United States. Other strategies may be considered to address some of these issues, such as advance directives and other forms of consumer-directed care planning such as wellness recovery action plans.

"If assisted outpatient treatment had been available to my paranoid schizophrenic son, countless heartaches and dangers could have been averted over the course of the 25 years he has endured this cruel disease. No, instead we have had to wait until our psychotic loved ones became a danger to self or others. There are red flags that maybe only family members can see, but still we have to wait until it is too late. My son has been homeless, dangerous, and now in prison. I have not heard from him in 3 years because I "know" he's been off meds, but he has a right to refuse treatment! He is lost! And I can get no information because of HIPAA. We need assisted outpatient treatment, revised HIPAA, and more hospital beds instead of jail cells."

—Judy (submitted through public comments to the ISMICC)

**Caregivers of people with mental illness face complex situations and a high burden of care.** A study of unpaid caregivers by the National Alliance for Caregiving estimates that nearly 8.4 million Americans provide care to an adult with an emotional or mental health issue, mainly related to SMI (NAC, 2016). It found that, for nearly one in five mental health caregivers, taking care of a loved one is equivalent to a full-time job. Approximately one in three caregivers provides care for more than 10 years (NAC, 2016). Many people with SMI are financially dependent on family and friends. Caregivers also bear a significant emotional burden, and often report feeling isolated and stigmatized because of their loved one's illness. This stress can lead to physical health problems, as nearly 4 in 10 caregivers report difficulty taking care of their own health, and about half cite caregiving as a cause of worsening health (NAC, 2016). Caregivers also face logistical challenges in coordinating care for their loved one, such as finding appropriate providers, managing medications, handling paperwork and finances, and accessing community services



(NAC, 2016). Despite their involvement in day-to-day disease management, many caregivers report they are often excluded from care conversations and cannot speak to the provider about the patient's condition. Parents caring for an adult child face these challenges more frequently, as 77 percent have been told they cannot speak to a provider and 69 percent feel they have been left out of care conversations (NAC, 2016).

## Serious Emotional Disturbances

The definition of SED is similar to SMI, but applies to children and youth; it requires the presence of a diagnosable mental, behavioral or emotional disorder and substantial functional impairment. While some of the diagnoses that contribute to meeting criteria for SED are the same as for SMI, some are different. Diagnoses that are more commonly seen in children than adults include disruptive behavior disorders, and others that are less commonly seen in children than adults, include bipolar disorder and schizophrenia.

As with SMI, individuals with SED can also have substance use disorders and intellectual/developmental disabilities that co-occur with their mental disorders. Those whose sole diagnosis is a substance use disorder or an intellectual/developmental disorder are not considered to have SED. The type of functional impairment in SED also reflects the nature of childhood; role functioning in family, school, and community naturally varies depending on the age of the child.

**Many children and youth have an SED.** It has been challenging to assess functional impairment across age groups, as no national survey currently estimates the prevalence of SED. SAMHSA estimates prevalence ranging between 6.8 and 11.5 percent, based on published studies that differ on the study design and ages of children and youth included.

Reviews of the literature have produced some estimates. According to a 2013 CDC review of population-level information, estimates of the number of children with a mental disorder range from 13 percent to 20 percent (CDC, 2013). A recent meta-analysis of U.S. epidemiological studies concluded that 10 percent of children meet the criteria of significant impairment in one domain of role functioning (family, school, peers, community, or school) (Williams, Scott, & Aarons, 2017).

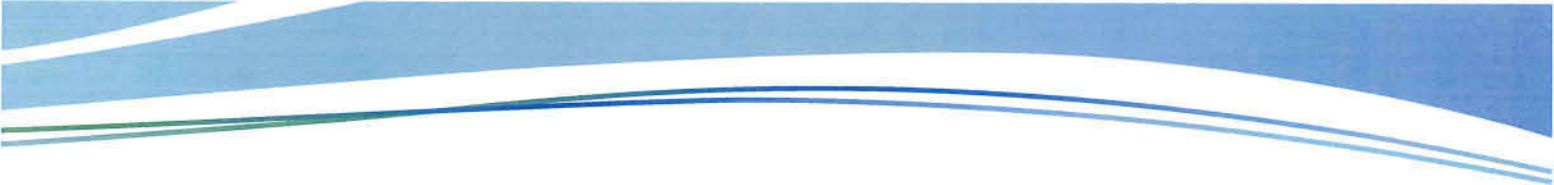
### Defining SED<sup>5</sup>

Serious emotional disturbance (SED) refers to children and youth who have had a diagnosable mental, behavioral, or emotional disorder in the past year, which resulted in functional impairment that substantially interferes with or limits the child's role in family, school, or community activities.

The members of the ISMICC have concerns about the term "serious emotional disturbance." The use of the word "emotional" does not capture the reality that mental disorders experienced by children and youth often have cognitive or behavioral aspects. The word "disturbance" also does not seem fitting for diagnosable disorders that are just as important to address in young people as disorders experienced by adults. As a result, ISMICC members plan to examine this issue and propose alternative language as the group moves forward.

<sup>5</sup> Adapted from Federal Register, Vol. 58, No. 96, pages 29422-29425; for detail on the criteria for emotional disturbance under IDEA, see <http://idea.ed.gov/explore/view/p/,root,regs,300,A,300.8,.html>.





The National Comorbidity Survey – Adolescent Supplement (NCS-A), was a large-scale national survey of youth ages 13 to 18 conducted between 2001 and 2004 (Merikangas, He, Burstein, Swanson, Avenevoli, Cui & Swendsen, 2010). Interviews of 10,123 youth used an instrument that generated DSM-IV diagnoses. The overall prevalence of disorders with severe impairment and/or distress was 22.2 percent. Lifetime prevalence of mood disorders (including major depressive disorder, dysthymia, and bipolar I and II) with severe impairment was the most common class of disorders (11.2 percent). Lifetime prevalence of behavior disorders (including conduct disorder and oppositional defiant disorder) with severe impairment was found at a rate of 9.6 percent, and the rate of anxiety disorder with severe impairment was 8.3 percent. By any measure, the problem is substantial, and addressing it is important for the healthy development of our nation's youth.

**Children and youth have a range of SED diagnoses.** SAMHSA's Children's Mental Health Initiative (CMHI) provides funds to a limited number of public entities to promote recovery and resilience for children and youth who have an SED and their families by providing comprehensive services for mental and substance use disorders using the system of care framework. Systems of care refers to a coordinated network of community-based services and supports organized to meet the challenges of children and youth and their families. Among youth entering the CMHI program in 2015, the five most common diagnoses were mood disorders (such as depression, 29.3 percent), attention deficit hyperactivity disorder (ADHD, 24.9 percent), oppositional defiant disorder (15.8 percent), adjustment disorders (15.3 percent), and post-traumatic stress disorder (PTSD) or acute stress disorder (12.6 percent) (CMHS/SAMHSA, 2016). Data from the 2016 National Survey of Children's Health (NSCH), shown in Table 1.2, indicate reported diagnoses for younger children, ages birth to 11, as well as for older youth. It should be noted that the NSCH methodology involves asking a parent about the statements made by a doctor or health provider, an approach that may be less precise and result in lower estimates than a diagnostic interview.

On average, 15 percent of young children (ages 2-8) in the United States have a parent-reported mental, behavioral, or developmental disorder (MBDD) diagnosis, which includes ADHD, depression, anxiety problems, behavioral or conduct problems such as oppositional defiant disorder or conduct disorder, Tourette syndrome, autism spectrum disorder, learning disability, intellectual disability, developmental delay, or speech or other language problems.<sup>1</sup> The percentage of children with diagnosed MBDD is similar for small rural and urban areas, at 18.6 percent and 15 percent, respectively (Robinson et al., 2017).

**Table 1.2. Weighted Data From 2016 National Survey of Children's Health**

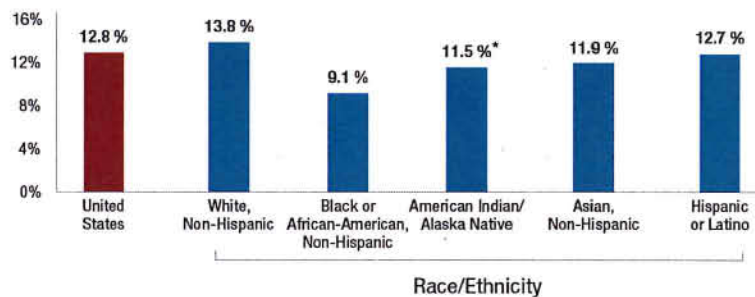
Condition	Percentage by Age Category:	
	Age 0-11 (N=48,534,964)	Age 12-17 (N=24,815,076)
Doctor/health provider ever said child had anxiety problems	4.4	12.4
Doctor/health provider ever said child had depression	1.1	8.2
Doctor/health provider/educator ever said child had behavioral/conduct problems	7.1	10.1

\* Missing data excluded from denominator

**Racial and ethnic differences among youth.** The NCS-A study found few differences across racial and ethnic groups in the major classes of mental disorders (mood, anxiety, or behavior disorders), except that the rates of anxiety disorders were higher and rates of substance use disorder were lower among Non-Hispanic Black or African-American adolescents, compared to Non-Hispanic White adolescents, and there were higher rates of mood disorders among Hispanic adolescents compared to Non-Hispanic Whites.

SAMHSA's ongoing National Survey of Drug Use and Health estimates the rate of major depressive disorder annually among youth. In 2016, 12.8 percent of youth in this age group (an estimated 3.1 million youth) experienced a major depressive episode (CBHSQ, 2017j). There were differences in the rate of major depressive episodes across ethnic groups, with Non-Hispanic Black or African-American youth having lower rates and Non-Hispanic White youth having higher rates (Figure 1.5).

**Figure 1.5. Past Year Major Depressive Episode Among Adolescents Ages 12 to 17 in the United States, by Race/Ethnicity: 2016**

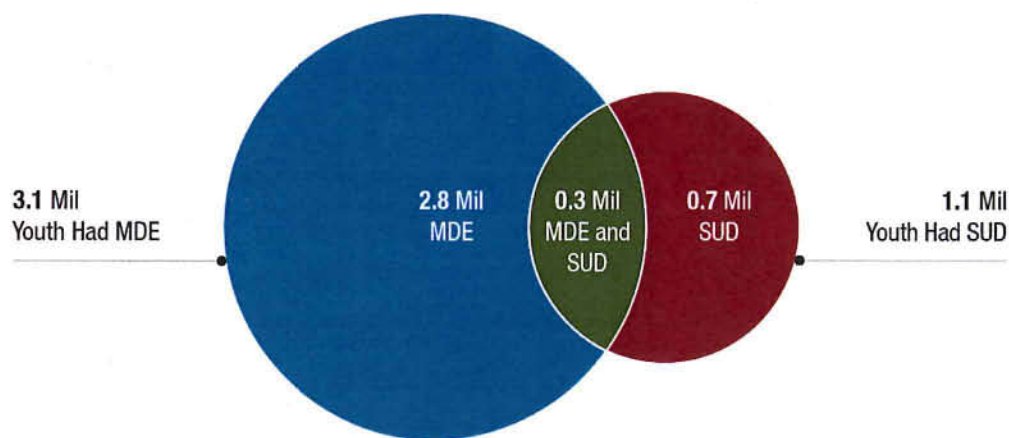


**Source:** Based on Table 9.7B of: Center for Behavioral Health Statistics and Quality. (2017). *Results from the 2016 National Survey on Drug Use and Health: detailed tables*. Rockville, MD: Substance Abuse and Mental Health Services Administration.



**Youth with SED often have multiple disorders.** The NCS-A study found that 6 percent of youth had disorders in two or more major classes of mental disorders (i.e., mood, anxiety, or behavior disorders). Among youth with a past year major depressive episode, 12.1 percent (an estimated 333,000) also had a substance use disorder (CBHSQ, 2017k). An estimated 333,000 adolescents ages 12 to 17 had both a substance use disorder and a major depressive episode in the past year (Figure 1.6). Children and youth with SED also have increased rates of co-occurring health conditions such as obesity (Pastor & Reuben, 2011), asthma (Goodwin et al., 2014), and the onset of cigarette smoking (Blum, Kelly, & Ireland, 2001).

**Figure 1.6. Past Year Substance Use Disorder (SUD) and Major Depressive Episode (MDE) Among Youth Ages 12 to 17: 2016**



**Source:** Adapted from Figure 66 of: Substance Abuse and Mental Health Services Administration. (2017). *Key substance use and mental health indicators in the United States: Results from the 2016 National Survey on Drug Use and Health* (HHS Publication No. SMA17-5044, NSDUH Series H-52). Retrieved from <http://www.samhsa.gov/data>.

**Early intervention is crucial to address development of mental disorders.** The vast majority of individuals who will develop a mental health disorder in their lifetime do so before age 24 (Kessler et al., 2005). Strong prevention and early intervention efforts should occur at these ages, but occur far too rarely. There are many standards for assessing mental health conditions in children and adolescents up to age 18 in pediatric care (U.S. Preventive Services Task Force, n.d.). There are also consensus-based guidelines for care of children and adolescents, such as Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents (Hagan, Shaw, & Duncan, 2017). These guidelines call for regular screening for a variety of mental health conditions, and include recommendations for pediatric screening of those up to age 21. Medicaid's Early and Periodic, Screening, Diagnosis, and Testing (EPSDT) benefit requires mental health assessment of all covered children. Other expert groups have developed guidelines for screening for a broader array of mental health conditions in children and adolescents (Weitzman et al., 2015). However, screening is recommended only when systems are in place to ensure accurate



diagnosis, treatment, and follow-up, so screening efforts must be accompanied by an expansion of access to mental health care. Low uptake of screening procedures likely reflects the shortage of mental health care for children and youth, the stigmatizing nature of these conditions, and cultural variations in views of mental health needs (Wissow et al., 2013). Mental health screening for children and adolescents can be conducted in schools (Essex et al., 2009), but the vast majority of schools do not conduct universal screening, as they face many of the same challenges as screening in pediatric care settings, and have limited resources to do so.

As youth enter young adulthood, mental health screening and early intervention continues to be limited. Screening rates are very low (IOM & NRC, 2014). Screening tools and processes have not been developed explicitly for 18- to 26-year-olds (Ozer, Scott, & Brindis, 2013). This is a critical age at which screening for development of the most serious mental illnesses (i.e., psychotic illness) can substantially reduce the impact of these disorders. Yet screening for early psychosis rarely takes place outside mental health clinics affiliated with early psychosis research programs. The following recommendation was issued by the National Academy of Science, Engineering, and Medicine (IOM & NRC, 2014): “The U.S. Preventive Services Task Force should develop a consolidated set of standardized evidence-based recommendations for clinical preventive services such as screenings, counseling services, and preventive medications specifically for young adults ages 18-26. Behavioral and oral health should be included in these recommendations.” This is an important step toward achieving a system of care that ensures screening for youth during this critical time.

**Children and youth with SED often have challenging life circumstances** (CMHS/SAMHSA, 2016). Caregivers of youth entering the CMHI program reported that 4 in 10 (39.7 percent) children and youth had been exposed to domestic violence at some point in life, and one in five (21.7 percent) had been exposed to such violence during the prior six months. More than one in five of these youth were missing school frequently, and nearly half (47.2 percent) had been suspended or expelled from school. Nearly three-quarters of these youth (73.5 percent) lived with someone who had shown signs of depression in the six months before entering services, and nearly half (48.4 percent) had a family member with a mental illness other than depression (CMHS/SAMHSA, 2016). These types of adverse childhood experiences increase the likelihood of developing SED and later SMI (Dube, Anda, Felitti, Chapman, Williamson & Giles, 2001; Chapman, Whitfield, Felitti, Dube, Edwards & Anda, 2004).

“Three years ago, I took in my cousin because my uncle and aunt are both SMI and they could no longer care for him. His mom was in jail and his father was in a long-term community placement. At only 8 years old, he was very much out of control due to a number of abuses and a general lack of a nurturing environment. We quickly pulled together the services and supports we thought he needed in school, in the community, and in our home. He was still failing miserably in all of his life domains. This year, I sat down with every provider he had ever used and we developed strategies, services, and supports that cut across all of his programs as a team. We developed new approaches that were customized to his unique needs and life experiences. Here we are today, I am finalizing his adoption and he is starting to mesh into our family and community. He is a survivor; but the system had to work collaboratively to throw him the lifelines he needed.”

— SJ



**Effective treatments are available.** There are a wide range of evidence-based treatments for many mental disorders that children and youth experience (e.g., anxiety, depression, ADHD, autism, eating disorders, obsessive compulsive disorder [OCD], exposure to traumatic events, disruptive behavior, substance abuse) (Silverman & Hinshaw, 2008). Psychotherapeutic or psychosocial services such as cognitive behavioral therapy and social skills training are evidence-based interventions that may be provided independently or along with medications. Coordinated specialty care is an evidence-based approach to working with youth nearing or in early adulthood who experience a first episode of psychosis. Psychotropic medications are commonly given for disorders such as anxiety, depression, psychosis, ADHD, and OCD, among others, and should be used for children and youth in keeping with the latest research and guidelines. Prescribers should be careful, as psychotropic medications have been overused in some populations of young people in ways that are not supported by research or practice guidelines (American Academy of Child and Adolescent Psychiatrists, 2015). In addition, the system of care approach continues to evolve to reflect advances in research and service delivery. The core values of community-based, family-driven, youth-guided, and culturally and linguistically competent services are widely accepted. The guiding principles calling for a broad array of effective services, individualized care, and coordination across child-serving systems are extensively used as the standards of care throughout the nation (Stroul & Friedman, 2011).

**Most children and youth with SED do not receive treatment.** Identifiable mental health problems are common, but few children receive services for those problems. The lack of services received by these young, multi-challenged children is a services systems and social policy failure (McCue Horwitz et al., 2012). About 4 in 10 (40.9 percent) of youth ages 12 to 17 with major depressive episodes (1.2 million youth) received treatment of any kind in 2016 (Figure 1.7) (CBHSQ, 2017j). This is similar to the findings from the NCS-A study, that 36.2 percent of adolescents with mental disorders received treatment across diagnostic groups. However, that study also reported that treatment rates were higher for adolescents with attention deficit hyperactivity disorder (59.8 percent) and behavior disorders, such as oppositional defiant disorder and conduct disorder (45.4 percent), but lower for those with anxiety disorders (17.8 percent), while children and youth with mood disorders had received treatment 37.7 percent of the time (Merikangas, He, Burstein, Swendsen, Avenevoli, Case, & Olfson, 2011). Among youth in 2016 with a past year major depressive episode who received treatment for depression, only 18.9 percent saw or talked to a health professional and also took prescription medication (CBHSQ, 2017l).

"The last 10 months of our lives have been filled with a life-altering and horrific change as my beloved youngest son had a psychotic break and was diagnosed with schizophrenia. Like many other families, we were naïve. We have been screaming for help and information, waiting on services, and watching my son slowly fade away. Things need to change. It is evident that mental illness is still treated with casual effort and not as a true and serious medical illness."

— Charlene (submitted through public comments to the ISMICC)